

Content and Implementation of a Caregiver Assessment

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INTRODUCTION

Caregiver assessment is a process of gathering information that describes a caregiving situation and identifies problems or concerns that may be addressed by interventions. Assessment information provides a rationale for developing a care plan, which sets goals and recommends appropriate interventions for improving a caregiving situation. Caregiver assessment begins with an initial information gathering effort, followed by periodic reassessments. Reassessments update initial information; identify new problems or concerns; and monitor progress, effectiveness, and interventions outcomes.

Assessment information may come from multiple sources, including direct questioning of caregivers and care receivers, observation, performance testing, and self-administered questionnaires. An assessment may have a structured format that includes limited open-ended narrative comments and a specific sequence to follow in soliciting information. Alternatively, it may be unstructured allowing flexibility in when and what information is gathered and rely on comments and narrative. Most assessments are a mix of both structured and unstructured information.

There are two major categories of activities in developing a caregiver assessment. First, the content needs to be established. Characteristics or constructs included in an assessment will vary depending on the particular focus of an intervention. This step also involves deciding how to measure each characteristic or construct so an accurate and consistent picture of the situation is obtained. Second, procedures for implementing and responding to assessment information need to be established. This includes creating guidelines specifying when the assessment should be completed, who will complete the assessment, whether all or only portions of items are mandatory, and how assessment information should be used to devise the care plan and recommended interventions.

TIPS FOR DEVELOPING AN ASSESSMENT

There is no need to start from scratch when developing a caregiver assessment. An assessment can be created by drawing on instruments developed by existing caregiver service programs and years of caregiving research. Existing assessment tools and research instruments provide the building blocks for designing a useful assessment no matter how unique the intervention.

A caregiver assessment should include information on care receivers as well as caregivers. Even when interventions focus exclusively on caregivers, characteristics of care receivers should be included to understand the context and challenges of the caregiving situation. The types and amounts of services caregivers will use depend on the nature of care receivers' impairments, services, and assistance. (Noelker & Bass, 1995).

A caregiver assessment should represent the network of family members and friends as well as the history of family relationships. Caregiving is best understood as a family issue involving multiple members including care receivers (Penrod, Kane, Kane, & Finch, 1995). Many of caregivers' difficulties and strengths come from their relationships with other family

members and friends. Information on the network of family and friends is especially important for interventions designed to mobilize or reorganize the informal care network.

An assessment should include all the information needed to determine whether a situation constitutes “caregiving” as defined by the intervention, since there is no standard definition and many helpers do not define themselves as caregivers (Barer & Johnson, 1990; Bass & Noelker, 1997). For example, interventions may be limited to family members assisting care receivers with certain types of illnesses or impairments (e.g., cognitive impairment), only family members who assist with selected types of tasks (e.g., daily living tasks), or certain types of relatives (e.g., spouses or daughters). Even if access to an intervention is unrestricted, the content or focus may be different depending on the type of caregiving situation.

Finally, the longer the assessment the more difficult and time consuming it will be to use. Many excellent, comprehensive assessments have been developed and never implemented because they were not practical. Although there are many interesting facts about every caregiving situation, an assessment should be limited to only essential items for designing the care plan, delivering interventions, and evaluating outcomes.

CONTENT OF A CAREGIVER ASSESSMENT

The content of a caregiver assessment should be determined in part by the focus of the intervention. For example, an intervention designed to reduce difficulties for working caregivers may require an assessment with more information on caregivers’ job characteristics and care-related work strain. An intervention designed to increase family members’ involvement in caregiving may need more information on the composition of the family network, including kin not involved who could be helping.

When selecting the content of an assessment, consider whether certain pieces of information can serve as outcomes for evaluating an intervention’s effectiveness. Characteristics most likely to function as outcomes are those that can change from initial to follow-up reassessments. For example, it may possible to examine whether strain decreases from the initial to follow-up assessments for interventions that have a goal of reducing caregiver strain. Keep in mind that improvements in outcomes may only be possible when the initial assessment shows some type of problem (Wheaton, 1985; Whitlatch, Zarit, & von Eye, 1991) and when sufficient amounts of the intervention are used after the initial assessment (Kosloski & Montgomery, 1995). Additionally, improvements from an intervention are more likely when there is close match between outcomes and the goals of the intervention (Burgio, et al., 2001). Expecting improvement in characteristics not specifically tied to the intervention might be unrealistic and lead to disappointing results.

Tables 1-3 present a broad range of constructs or characteristics that might be considered for inclusion in a caregiver assessment. Space limitations prevent an extensive discussion of the importance and rationale for each characteristic. However, all those listed may impact or represent the caregiving situation and, depending on the intervention, may be considered for inclusion.

Table 1 presents assessment characteristics for measuring the caregiving context, health and functional status of care receivers, and task assistance provided by caregivers. Two of the more important measures of the caregiving context are relationship of the caregiver and care receiver, and whether the care receiver and caregiver share a household.

| Table 1: <i>Intensity of Caregiving</i> |
|--|
| Caregiving Context |
| <ul style="list-style-type: none"> • Demographics: Age, Gender, Race, Education, Marital Status & Veteran Status of Care Receiver and Caregiver |
| <ul style="list-style-type: none"> • Relationship of Care Receiver & Caregiver |
| <ul style="list-style-type: none"> • Shared or Separate Household |
| <ul style="list-style-type: none"> • Family and Household Composition for Care Receiver and Caregiver |
| <ul style="list-style-type: none"> • Emotional Support |
| <ul style="list-style-type: none"> • Employment Status of Caregiver |
| <ul style="list-style-type: none"> • Other Caregiving Demands |
| <ul style="list-style-type: none"> • Income |
| Health and Functional Status of Care Receiver |
| <ul style="list-style-type: none"> • Name Health Plan and Primary Care Physician |
| <ul style="list-style-type: none"> • Most Recent Physician Visit |
| <ul style="list-style-type: none"> • Primary and Secondary Diagnoses |
| <ul style="list-style-type: none"> • Recent Hospitalizations or Emergency Department Visits |
| <ul style="list-style-type: none"> • Personal Care and Supervision Task Dependencies |
| <ul style="list-style-type: none"> • Instrumental Activities of Daily Living Dependencies |
| <ul style="list-style-type: none"> • Physical Disability |
| <ul style="list-style-type: none"> • Cognitive Impairment and Behavioral Problems |
| <ul style="list-style-type: none"> • Established Advanced Directives |
| Task Assistance Provided by Caregiver |
| <ul style="list-style-type: none"> • Personal Care Tasks |
| <ul style="list-style-type: none"> • Daily Living Tasks |
| <ul style="list-style-type: none"> • Health Care Tasks |
| <ul style="list-style-type: none"> • Care Management Tasks |
| <ul style="list-style-type: none"> • Supervision Tasks |

In terms of relationship, most caregivers are daughters, daughters-in-law, wives, or husbands of care receivers. In designing interventions, differences between spouse and non-spouse caregivers often are highlighted. Spouse caregivers are older, have more health problems,

suffer more negative caregiving consequences, resist the use of services and involvement of others in care, and are more committed to maintaining the care receiver at home rather than in a nursing home (Wright, Clipp, & George, 1993; Pruchno, Michaels, & Potashnik, 1990). Spouse caregivers wait longer before accepting supportive interventions, which may necessitate special marketing strategies and may limit the effectiveness of interventions that are more effective before problems become crises.

Caregiving in shared and separate households also shows important differences. Because most spouse caregivers live with care receivers, these differences pertain to non-spouse caregivers. Research suggests that for non-spouses, living arrangement or household composition, rather than relationship may have a greater impact on the caregiving experience (Deimling, Bass, Townsend, & Noelker, 1989). Caregivers in shared households have heightened vulnerability because they spend more time caregiving, are more committed to maintaining care receivers at home, and, generally, report more negative caregiving consequences such as depression, social isolation, and health deterioration. Caregivers in separate households more often function as care managers who rely more on others to provide direct care (Archbold, 1983). These caregivers report more relationship difficulties with care receivers, possibly due to stress from competing demands or feelings they are not providing enough help because they do not reside with care receivers (Deimling, et al., 1989). Needs of caregivers living in separate households are more apt to be overlooked because they often are not present when services are delivered to care receivers.

Two other characteristics of the caregiving context, caregiver employment status and other caregiving demands, may be central for an assessment and for targeting supportive interventions. Many caregivers struggle to balance demands of work and caregiving, especially as a greater number of women have entered the labor force (Scharlach & Boyd, 1989). Additionally, a sizeable number of caregivers are assisting more than one older relative and/or simultaneously caring for dependent children (Brody, 1981). Maintaining multiple work and caregiving roles may lead to cumulative stress and feelings of being overwhelmed (Neal, Chapman, Ingersoll-Dayton, & Emlen, 1993). Interventions that assist in finding or arranging formal services, or with expanding/reorganizing the informal care network, may be especially helpful in these situations.

The second category of characteristics in Table 1 represents care receiver health and functional status. Among the characteristics is personal care dependencies or difficulties with activities of daily living. The need for assistance with personal care activities is a common cause of caregiving and include help with bathing, dressing, grooming, toileting, eating, and mobility within the home (Lawton & Brody, 1969). The need for supervision also is included with personal care activities and is very important when care receivers are cognitively impaired (Bass & Noelker, 1997). Dependencies in instrumental activities of daily living represent the need for assistance with more complex tasks such as housecleaning, laundry, shopping, and paying bills (Lawton & Brody, 1969; Pfeffer et al., 1982). Eligibility for care receiver or caregiver interventions is sometimes restricted to situations where these types of assistance are needed.

Physical disability, cognitive impairment, and behavioral problems are three dimensions of care receiver impairment. Physical disability refers to difficulty with basic movements such as stooping, bending, range of motion, gait, and strength (Nagi, 1976), while cognitive impairment

assesses care receiver memory problems. Some measures of cognitive impairment are derived from caregiver reports of symptoms such as forgetfulness, confusion, use of incorrect words, and inability to remember basic factual information such as street address or names (Deimling & Bass, 1986). Other measures of cognitive impairment require direct communication with care receivers and are considered more objective. Examples include mental status tests such as the Mini Mental State Exam (Folstein & Folstein, 1975) and the Short Portable Mental Status Questionnaire (Pfeiffer, 1975). While both types of measures could provide important information, it may be essential to understand caregivers' subjective perceptions since they are the targets of many supportive interventions.

Negative behavioral symptoms include wandering, yelling or swearing, interfering with the activities of other family members, and acting agitated or aggressive (Deimling & Bass, 1986; Cohen-Mansfield, Marx, & Rosenthal, 1989). Negative behavioral symptoms are the most stressful for caregivers and are related to increased caregiver strain, depression, and nursing home placement (Bass, McClendon, Deimling, & Mukherjee, 1994; Pruchno, et al., 1990).

The final category of items in Table 1 represents task assistance provided by the caregiver. Six task categories are included in the Table. These categories can be expanded into individual tasks. One expanded list includes 47 individual tasks and obtains task-by-task information on whether the caregiver helps, the frequency help, and perceived difficulty of help (Noelker & Bass, 1994).

Table 2 presents characteristics for assessing caregivers' emotional and physical status. Characteristics are divided into two categories: 1) caregiver well being and 2) caregiving consequences. Changes in these characteristics may be outcomes of interventions, with initial assessment results used as baseline indicators and follow-up assessment information used as outcomes. Caregiver well being differs from caregiving consequences by not explicitly being linked to caregiving. Well being measures represent caregivers' overall emotional and physical states with caregiving being only one of many factors that may impact these ratings. Caregiving consequences, on the other hand, specifically represent the perceived impact of caregiving. A more complete understanding of caregivers is obtained when measures of both well being and caregiving-specific consequences are included in an assessment (Stull, Kosloski, & Kercher, 1994). However, it may be more difficult for a caregiving intervention to impact well being since it is a product of many domains of life.

| Table 2: Caregiver Emotional and Physical Status |
|--|
| Well Being |
| • Self-Rated Physical & Emotional Health |
| • Health Conditions and Symptoms |
| • Recent Hospital Admissions or Emergency Department Visits |
| • Depression |
| Caregiving Consequences |
| • Tasks Difficulties |
| • Dyadic Relationship Strain |
| • Family Relationship Strain |
| • Caregiving Mastery or Self Efficacy |
| • Perceived Emotional & Physical Health Deterioration |
| • Social isolation |
| • Role Captivity |
| • Work Strain |
| • Financial Strain |
| • Prescription Drug Use Because of Caregiving |
| • Alcohol or Non-Prescription Drug Use Because of Caregiving |
| • Caregiving Satisfaction |
| • Caregiving Mastery |

Characteristics included under well being in Table 2 are only a small sample of various measures that could be appropriate for an assessment. Decades of work in the fields of psychology, sociology, and health sciences have been devoted to developing standardized instruments to measure different aspects of well being and it would be difficult to argue that one is superior to another. For example, anxiety and affect are not in the Table but are frequently used substitutes for depression, which is included.

Depression is one of the most frequently used constructs measured in caregiving research. There are many standardized sets of questions designed to assess depression, some with 20 to 30 items (Radloff, 1977; Sheikh & Yesavage, 1986), others that are reduce length versions of longer instruments (Kohout, et al., 1993), and even single-item indicators (Mahoney, 1994). The literature on the strengths and weaknesses of the various measures is easily accessible and will help in making decisions about which instrument is most appropriate.

The concept of caregiving consequences has a much shorter history than well being, although the past two decades of research provide considerable guidance in understanding this

construct and selecting indicators for an assessment. A weakness of existing research is in the area of positive caregiving consequences, with only limited studies of rewards and satisfactions of caregiving (Lawton, et al., 1989). There is a great deal of indirect evidence suggesting that positive aspects balance or offset the negative, an idea consistent with findings from the majority of studies that show most caregivers do not report substantial negative caregiving consequences (Wright, et al., 1993). An assessment that provides a balanced and accurate picture should not overlook positive experience that may come from helping a loved one.

The first item in Table 2 under caregiving consequences is task difficulties or caregivers' perceptions of tasks that are onerous. For tasks reported to be difficult, it may be helpful in care planning to know whether certain aspects of task assistance are more problematic, such as the physical demands of performing tasks, emotional discomfort or embarrassment, resistance by care receivers, or the frequency of help. Information on difficulties can be obtained for each individual task (e.g., bathing, dressing, toileting), each task category (e.g., personal care), or by one overall rating for all tasks caregivers help with. The amount of detail may depend on the importance of this information for allocating the intervention.

The next eight constructs in the Table 2 represent different dimensions of caregiver strain. Instruments exist for each dimension (Bass, et al., 1994; Deimling, 1994; Pearlin, et al., 1990; Stull, 1996). Measures of caregiver strain can be asked during a clinical interview or given to caregivers in a self-administered form. The dimensions of caregiver strain should be differentiated, since caregivers may experience only one or two types of strain and interventions may only need to address these particular problems. For example, some wife caregivers may have problems with social isolation, rather than work or financial strain. The assessment should enable a clinician to identify the distinct problem of social isolation so that it can be a focus of interventions.

The final two rows in Table 2 include two positive consequences of caregiving: satisfaction and mastery. Caregiving satisfaction comes from feeling pleasure from helping, knowing that the best care possible is being provided, enjoying the time spent with care receivers, and feeling closer to care receivers because of helping (Lawton, et al., 1989). Caregiving mastery represents caregivers' self-confidence about being able to successfully provide quality assistance to care receivers (Lawton, et al., 1989; Pearlin & Schooler, 1978). Mastery is reflected, for example, in caregivers' feelings that they are competent at meeting care receiver needs, knowing how to handle problems that arise, and learning skills for filling the caregiver role.

Table 3 includes characteristics of informal support, current and recent formal service use, and coping resources. These characteristics are potential strengths that can offset or protect caregivers against negative caregiving consequences. Although most research suggests these characteristics are beneficial (Bass & Noelker, 1997), they can have adverse effects if the assistance offered is unreliable, of poor quality, or does not match the needs of caregivers and care receivers (Kahana et al., 1994; Silver & Wortman, 1980).

Table 3: Informal Support, Formal Service Use, and Coping Resources

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| Informal Support |
| • Number and Composition of Informal Helpers for Care Receiver |
| • Perceived Quality of Informal Support for Care Receiver |
| • Number and Composition of Informal Helpers for Caregiver |
| • Perceived Quality of Informal Support for Caregiver |
| Current and Recent Formal Service Use |
| • Types and Amounts of Formal Services Currently and Recently Used by Care Receiver |
| • Satisfaction with Care Receiver Formal Service Use |
| • Types and Amounts of Education and Support Services Currently and Recently Used by Caregiver |
| • Satisfaction with Caregiver Education and Support Service Use |
| Coping Resources |
| • Problem-Focused |
| • Emotion-Focused |

The first category in Table 3 reflects informal support, which includes the network of family members and friends who assist caregivers and care receivers. It also may include family and friends who do not assist at the time of the assessment but who could be called upon to help if needed. Table 3 distinguishes support for care receivers and caregivers. In some cases, particularly spouse caregiving situations, there will be considerable overlap in the two networks, while in other situations helpers will be assisting one party but not the other.

There are a variety of formats used to collect information on informal support. Some approaches ask caregivers to draw pictures of their helping networks that include names and relationships of helpers. One version places the name of the caregiver or care receiver in the center of a circle with all helpers' names and relationships listed around the name in the center (Kahn & Antonucci, 1980). The distance between the caregiver's or care receiver's name listed in the center and each helpers name visually represents the importance of each helper. Other approaches ask caregivers to list family members and friends who help, followed by a series of questions about what each person does, how often they do it, and how important or satisfied caregivers are with each helper (Benjamin Rose Institute, 1992).

When assessing informal support, it is important to assess both quantitative aspects of the network, meaning number of helpers and their relationships, and quality of help provided. Most research suggests quality is more important than quantity with a small number of more helpful persons better than a large number of less helpful persons (Wright, et al., 1993). Quality is a subjective concept and may be based on caregivers' ratings. Clinicians may provide a more objective assessment of quality based on their expert judgment and experience. While quality is

prominent in the literature, there may be benefits of having a larger network when there is a need to distribute tasks from caregivers to other family and friends in order to provide relief or respite (McCarthy, Bass, & Eckert, 1995).

The second category of items in Table 3 focuses on formal services. Especially in long-term caregiving, many care receivers and/or caregivers will have prior or current experience with formal services, including caregiver interventions. Past service experience has an important impact on caregivers' receptivity to new interventions (Bass, McCarthy, Eckert, & Bichler, 1994). Additionally, knowledge of currently used services is essential for coordinating care and developing an effective care plan.

Many assessments include a list of different types of services for care receivers (e.g., home nursing; personal care or home aide service; meals; transportation; counseling or emotional support; case management) and ask caregivers to indicate which are currently being used, which have been used during the past six or 12 months, and how satisfied they were/are with each service. For services used in the past but no longer being used, it may be helpful to know why the service was stopped.

A similar approach can obtain information on current and past use of caregiver services. A list of caregiver services could be limited to education and support services (e.g., information and referral; telephone support; education programs; respite programs; reading, audio, or visual materials on caregiving), or it also may include health services.

Coping resources is the final category in Table 3. Coping resources refer to actions or ways of thinking that help caregivers deal with caregiving difficulties. From an intervention point of view, some caregivers may benefit from learning alternative ways of coping or from reexamining ways of coping that are perceived as being of limited effectiveness. However, there is little consensus on whether certain coping strategies are inherently more or less effective (Silver & Wortman, 1980), and it is difficult to argue that caregivers should change or avoid certain coping strategies unless they are perceived by caregivers to be inadequate or unhelpful.

Coping resources include a wide variety of strategies; some are internal to the person and part of personality, while others are situational and external (Lazarus & Folkman, 1984). Coping strategies change over time and in response to changes in the situation (Zarit, 1989). Although formal support and informal services are treated separately in Table 3, they also are coping resources.

Two categories of coping resources are listed in Table 3: problem-focused and emotion-focused (Lazarus & Folkman, 1984). Problem-focused coping include instrumental actions or thoughts that attempt to find alternative ways of dealing with or redefining the situation. For example, learning more about caregiving issues, doing activities that give caregivers a break from helping, or rearranging the caregiving schedule or environment. Emotion-focused coping are thoughts or behaviors designed to lessen distress by changing the response to the situation. Examples include expressing or hiding emotions, finding meaning in caregiving, trying not to think about caregiving difficulties, and relying on faith or prayer.

IMPLEMENTING A CAREGIVER ASSESSMENT

While there are many sources from which to model content of an assessment, much less is known about successful implementation. Ideally, a caregiver assessment is implemented in a standardized fashion for all caregivers, with complete information obtained in a timely manner. Information gathered in an assessment should identify problems that can be addressed by caregiver interventions recommended in the care plan. This information should be updated by periodic reassessments. All too often, successful implementation is elusive, with assessments only sporadically or partially completed and assessment information not linked to the care plan.

Three common reasons may explain why the implementation of assessments is not more successful. First is logistic problems related to the amount of time it takes to complete the assessment. Service providers often feel pressure from supervisors and funders to devote as much time as possible to direct service. Although part of direct service, an assessment that is too lengthy or includes information irrelevant to a particular client's situation may be perceived as a waste of direct service time. Providers may feel the assessment adds to the already excessive burden of mandated paperwork and documentation. This frustration increases when assessment information duplicates what has been collected during intake or at some other point in the service process.

Second, some service providers complain that a standardized assessment hampers their ability to develop trust and rapport with care receivers or caregivers. If forced to ask probing or threatening questions before a level of comfort is reached, providers worry that reluctant service users will refuse help. This is most problematic when all elements in an assessment are mandated to be completed during first or second service contacts.

Third, there often is concern that an assessment interferes with the natural flow of the clinical process. This occurs when providers are forced to collect assessment information that bring up concerns that cannot be addressed by available interventions or raises issues before caregivers are ready to confront them. This may lead caregivers to have unrealistic expectations about assistance that can be provided.

Table 4 presents tips that may be helpful for successfully implementing a caregiver assessment. Several items in the table suggest flexibility in when and how an assessment is completed. Flexibility in the timing of completion must be balanced against the need for this information to be used in developing the initial care plan. Some components may be more urgent than others and should be required first. Allowing some leeway for the remaining items, such as by the end of the first month of service use, may decrease concerns about rapport and interference with the clinical process.

Table 4: Tips For Implementing a Caregiver Assessment

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| • Allow flexibility in when the assessment is completed |
| • Allow flexibility in methods of collecting assessment information |
| • Consider whether certain parts of the assessment can be self-administered by caregivers |
| • Control length by designating some sections as optional based on a filter question |
| • Eliminate the collection of information redundant with other available record data |
| • Use only essential items needed for a valid and reliable measures of each characteristic |
| • Simplify answer categories when adapting measures from research and other assessments |
| • Give providers who complete assessments feedback or results on a regular basis |
| • Show the assessment is worthwhile by linking it to the care plan service interventions |
| • Use computer applications to streamline or ease the assessment process |

Flexibility in methods means that different techniques can be used to obtain assessment information. Some providers may choose to use the assessment as a structured interview, while others may change the order of items and follow the natural flow of discussion. Alternatively, handing or mailing some sections of the assessment to caregivers for self-administration can be an efficient way to obtain information while reducing burden on providers and allowing caregivers time to think about their responses. When there is flexibility in collection procedures, it may be important to include in the assessment a checklist that indicates who provided certain pieces of information and how it was obtained. Knowing the sources of assessment information (e.g., direct observation versus caregiver responses) and methods used to collect assessment information (e.g., self administered form versus clinical interview) may be necessary for an accurate interpretation.

Another idea presented in Table 4 is to control the length and complexity of the assessment. This means only essential information should be included with each item having a specific purpose related to care planning, evaluating outcomes, or effective clinical or administrative functioning. Instruments taken from research studies or existing assessments should be carefully scrutinized and shortened if it does not jeopardize the integrity of the measure. Getting suggestions from persons who developed existing measures may help in deciding how to shorten a previously used instrument. Use of existing measures also may be more practical if answer categories are simplified. For example, when adapting a research measure that uses four response categories from “strongly agree” to “strongly disagree,” it may be sufficient to use only two response categories of “agree” and “disagree.” Another strategy to control length is to eliminate the collection of duplicate information obtained at other points in the service delivery process. For example, intake departments may gather a variety of information about the caregiving context, which can be transferred into the assessment.

Finally, successful implementation is facilitated by showing providers that the information is being used for care planning, service delivery, program administration, and/or

evaluating outcomes. Any feedback that summarizes results of assessments helps providers feel that their efforts are useful and worthwhile.

AUTHOR DESCRIPTION

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